

Pauline McRae, 19 Bagley Terrace, Waterbury CT

Dear Members of the Appropriations Committee,

My name is Pauline McRae and I live in Waterbury. I am the long-term foster mother of 3 daughters – ages 12, 13, and 23 – all of whom have developmental disabilities and are medically fragile.

I want to thank the Appropriations Committee for your strong support for families like mine who have chosen to receive care services in our homes. However, despite the needs of families like mine, Governor Malloy's recent budget proposal doesn't include sufficient funding to meet those needs on the DDS home care waiver programs.

As I mentioned, all three of my daughters have developmental disabilities. My eldest has been with me since she was 6 years old and the other two have been with me since they were babies. I have cared for clients with developmental disabilities for almost 30 years, but I chose to take on the cases of my daughters because few parents are willing to assume custody of medically-complex foster children. All of my daughters are like my flesh and blood, and I love them as my own.

My eldest daughter receives funding for home care services through DDS and we have four Personal Care Attendant caregivers (including me), paid for by the State DDS Medicaid waiver.

She cannot urinate or make a bowel movement without the help of others, so she has to be catheterized every 4 hours and receive a medical procedure to have a bowel movement. We are teaching her to become as independent as she can be, but we still

have to bathe her, comb her hair, brush her teeth, and feed her. She also has seizures and cannot be left alone, and her caregivers must know how to protect her airways when she has a seizure to keep her safe. She sleeps with a C-PAP on her face so you must make sure it is properly maintained and set up every night. She also has numerous medical appointments that she needs to be transported to, including to monitor a shunt in her head. We have to lift her and move her from point A to point B, including repositioning her every 4 hours.

I paint this picture so you can see how physical it is to provide this kind of care, and how vital that funding for DDS home care services is for my daughter's day-to-day life. We need more funding for DDS home care than what's proposed in the Governor's budget, and I hope you will find a way to help families like me.

On top of that, we have a long-standing challenge in making the best use of our already-limited DDS services budget for my daughter. We need every dollar to be able to hire the home care help she needs. But DDS does not provide an affordable workers' compensation insurance policy to cover the home care workers we hire through the Medicaid home care waiver. This means I have to use those DDS dollars to purchase an expensive individual insurance policy — so we are sacrificing many hours of care my daughter needs to instead buy an insurance policy to protect us from a possible lawsuit if someone gets hurt on the job in our home. There is a better, more cost-effective way, and I hope you will address this in your budget proposal. This is in the best interest of care for my daughters and would be the most cost-effective.

Thank you for your time.